Today, individuals have greater access to information about their health than ever before (Randeree, 2009; Eysenbach, 2008). Much of this change is due, in large part, to advances in biotechnology and the sequencing of the human genome (Manolio & Collins, 2009). It is now possible, for example, for individuals to log onto the Internet and, for a fee of several hundred dollars, order an at-home DNA collection kit and have the results of a myriad of genetic tests delivered directly to their e-mail inbox (Gurwitz & Bregman-Eschet, 2009). In some cases, these test results may indicate personal risk for common chronic diseases, such as certain forms of cancer, diabetes, cardiovascular disease, and several others. Companies marketing these test kits often claim that promoting greater access to and awareness of the association between genes and health, and one’s genetic susceptibilities to disease, leads to more proactive and insightful methods of individual health management (Hogarth, Javitt, & Melzer, 2008). Moreover, it is consistent with an emerging trend in medicine – that of consumer-oriented medicine – which places health information tools directly in the hands of patients under the premise of fostering better patient-provider collaboration (Silvestre, Sue, & Allen, 2009).

Though the principles behind this direct-to-consumer approach to genetics seem laudable and perhaps even exciting, there is considerable controversy as to what, if any, utility the information actually holds (Geransar & Einsiedel, 2008; Wasson, Cook, & Helzlsouer, 2006). Unlike genetic tests that are diagnostic (e.g., chromosome analysis for Down syndrome) or highly predictive (e.g., BRCA1 and BRCA2 testing for hereditary breast-ovarian cancer risk), this new wave of presymptomatic predictive genetic tests for common disease yields results that are much more uncertain because the statistical models on which they are presently based are imperfect and with limited data (Ng, Murray, Levy, & Venter, 2009).

The above scenario raises many questions for today’s health-care consumers. For example, for whom is this information applicable, and for what populations or subpopulations is it not? Under what circumstances might this information be useful, and when should it be disregarded as irrelevant? And perhaps most importantly, what, if anything, can be done in light of information about personal genetic risk to effectively lower the odds of becoming sick and raise the odds of staying healthy?
Because the prevalence of most diseases varies as a function of age, gender, race/ethnicity, and other personal characteristics, answers to these questions are complex and many are just beginning to be understood (Khoury et al., 2009). Some experts have concluded that the answers to such questions remain out of reach at the present time and may continue to be elusive for another 5–10 years (Frazer, Murray, Schork, & Topol, 2009). Yet, twenty-first century health-care consumers, providers, and policy makers face these choices now about incorporating personal genetic information into health management and often do so without a complete and accurate understanding of the potential impact of their decisions on multiple levels (Carlson, 2009).

As a society, we are just beginning to come to terms with how information from the revolution in genetics affects the health and well-being of the population (Ozdemir et al., 2009; Kunstmann & Epplen, 2006) and that of its most valuable resource – our children (Duncan, Savulescu, Gillam, Williamson, & Delatycki, 2005). In many respects, the above scenario captures an ongoing tension in genetics at present – one resting at the nexus of biotechnology, human genome science, and our ability to safely and effectively deploy and translate the results of genetic tests for individuals in full scope of their meaning to human health (Editorial, 2008; Kaiser, 2007). Traditionally, this latter role was performed through the health-care system by professionals trained and board-certified in medical genetics or genetic counseling. As genetic testing proliferates both within and outside of the health-care environment, it challenges traditional models of genetic health-care delivery and calls for a means to respond to this reality (Deverka, Doksum, & Carlson, 2007; Woodcock, 2007).

Though we do not yet know how rapidly this change will take place, or what form it may eventually assume, it is reasonable to anticipate that change is coming. Genetic testing is no longer confined, for example, to the realm of obstetrics and the choices that pregnant couples face when learning about the well-being of their unborn child. Likewise, it is no longer confined to pediatrics, the diagnosis and care of children with very rare diseases, and the coping experiences of parents who may have passed on disease-conferring risks to offspring. Today, genetics is part of virtually all medical specialties, particularly those involved in delivering primary care services to patients (Baird et al., 2009).

This emerging paradigm shift in the way that individuals may access genetic information (e.g., in clinical settings or online), and choose to interact with it (e.g., with or without the guidance of a qualified health-care professional), serves as an important referent point for this volume. Simultaneously, this is a landmark era of opportunity for social and behavioral scientists to help translate basic science discoveries from the genetics lab into better patient care and improved health outcomes for all (Patenaude, Guttmacher, & Collins, 2002), including young people (Tercyak, 2009; McBride & Guttmacher, 2009). It is also a time to examine robust and interrelated sets of questions surrounding which individuals might be interested in learning information about their personal genetic risk for disease, how individuals process and understand genetic risk
information, and (most importantly) how they may change their health behaviors in response to such news (McBride et al., 2008).

Health psychology, or psychology’s contribution to the interdisciplinary fields of behavioral and preventive medicine, is often aligned with the activities of primary care (Kessler, 2009). At its core, health psychology advances knowledge and understanding about the relationship between behavior and health, health promotion, and disease prevention (Sallis, Owen, & Fotheringham, 2000). As a discipline, health psychology has been translating the genetic aspects of behavior–disease relationships to health for more than a decade (Plomin, 1998; Lerman, Croyle, Tercyak, & Hamann, 2002). Health psychology often works alongside other medical and public health specialties to further the pursuit of knowledge in this area, most notably with those working in the domains of gene–behavior relationships and gene–health relationships. Together, these and other disciplines have helped to solidify and redefine a biopsychosocial model of medicine by integrating the social, psychological, and behavioral dimensions of health and health care (Engel, 1977; McClearn, 2004) with a new and emerging emphasis on genetics and personalized medicine (see Figure 1).

![Figure 1](image-url)

**Figure 1.** Interrelationships among the study of genes, behavior, and health.

Personalized medicine (also called systems medicine) has been defined as the application of molecular genetic information to health-care, with the goal of tailoring medicine to better meet the needs of given individuals (Janssens & van Duijn, 2008). Endeavors subsumed under the rubric of personalized medicine are numerous and include predictive genetic tests to identify persons at risk of developing certain health conditions, preventive therapies that are specific to this risk profile to help reduce it, and evidence-based approaches that are most likely to be successful in treating disease states that are based on risk analyses (Janssens & van Duijn, 2008).
One of the greatest and most anticipated potentials for personalized medicine is its impact on the prevention of disease states, especially when carried out among unaffected, healthy individuals (Kawamoto, Lobach, Willard, & Ginsburg, 2009). If one follows a personalized medicine approach incorporating predictive genetic testing to its logical conclusion, then primary prevention of disease before any signs of that disease may emerge is a highly laudable goal. Though there has been progress toward reaching this outcome, significant hurdles in medical education and health-care policy remain (Federoff & Gostin, 2009). Few health-care providers are well trained, for example, in behaviorally based approaches to disease prevention, and there is often too little time and incentive for providers to make prevention more of a priority (Pollak et al., 2008). There is currently thin evidence that incorporating the results of genetic tests and other biomarkers of potential harms to health into prevention-based health-care messages motivates or produces stronger or longer lasting behavior change (McClure, 2001). In light of this, some have questioned the wisdom of this approach over more traditional and effective forms of risk assessment (e.g., taking a detailed family health history) and noted the value of more integrated perspectives within primary care (Gartner, Barendregt, & Hall, 2009; Rich et al., 2004).

A majority of the work in personalizing medicine takes place with a focus on adults. For example, there has been a proliferation of genetic tests that may be used in the identification of adult cancer risks (e.g., BRCA1 and BRCA2 mutations) (Willey & Cocilovo, 2007; Arsanious, Bjarnason, & Yousef, 2009) and likely response to chemotherapy and other treatment regimens (e.g., genetic tumor profiling) (Slodkowska & Ross, 2009). Yet, we are reminded that much of the history of genetics in medicine is focused on the health and well-being of children, adolescents, and their families (Rimoin & Hirschhorn, 2004). We are also reminded of the special considerations that must take place anytime that children and adolescents are involved in therapeutic and nontherapeutic clinical trials, and that this can impact the pace of discovery in pediatrics (Wendler & Forster, 2004). Within the context of personalized medicine approaches to health and health-care, and its focus on primary prevention, far more work is needed to help translate these results to children. Though there are some promising steps forward in childhood cancer (Rabin, Man, & Lau, 2008), asthma (Koster et al., 2009), epilepsy (Glauser, 2002), and psychiatry (Stein & McGough, 2008), more are needed (Leeder, 2003). The disparities in personalized medicine research taking place with and for adults relative to similar work taking place with and for children and adolescents are striking.

Perhaps one way to help advance this conversation might be to adopt more of a lifespan perspective on health (commonly used in the field of developmental psychology) to facilitate our understanding of variations and nuances in the timing and onset of disease processes (Eaton, 2002; Tercyak, 2008): the National Children’s Study is but one example of this perspective (Branum et al., 2003). Though such works take many years to accomplish, the potential benefits to society that result from exploration of chains of biological and environmental processes (e.g., epigenetic
processes), and the importance of early-life experiences in the programming of adult health, are substantial (Solomons, 2009; Wadhwa, Buss, Entringer, & Swanson, 2009). These experiences include the family environment in which children are raised, the quality of the health-care received pre- and post-natally, the diet, the physical activity, and other lifestyle behaviors established early on that may track into adulthood, and the decisions and actions that children, adolescents, and their families take that promote or compromise both short- and long-term health outcomes (Shonkoff, Boyce, & McEwen, 2009). When considered in conjunction with genetics and the results of genetic tests, these factors may someday bring us a step closer to realizing the potential of personalized medicine for young people (Arnold & Jones, 2009; Balistreri & Helton, 2009). The results of large-scale gene sequencing efforts answering fundamental questions about the heritability of common disease will further drive this discovery process (Maher, 2008).

Thus, it is timely to reflect on the state of the science in health psychology and related disciplines that are concerned with translations and linkages among genes, behavior, and health and, specifically, the impact of the rapid emergence of such data for children, adolescents, and their families. In doing so, it is important to keep in mind continuity and discontinuity in the use of the terms “genetic” and “genomic” as typically encountered in the literature. Defined, genetics usually refers to the study of single genes and their impact on health. Genomics, by contrast, refers to the study of all genes and the interactions of genes with other genes and the environment to impact health. Both genetics and genomics are important to the discourse on this topic, as single genes, multiple genes, and their interaction with the environment hold meaning for healthy development among families.

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